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ABSTRACT

This newsletter issue gives people with disabilities the opportunity to educate others about self-advocacy. Twelve of its 17 articles are by individuals with disabilities who are self-advocates, or by other representatives of self-advocacy organizations. It includes information on self-advocacy strategies and examples of its impact on lives. Article titles and their authors include: "Out of My Old Life and into My New One" (Michael J. Kennedy); "A Short History of American Self-Advocacy" (Bonnie Shoultz); "Starting Local Self-Advocacy Groups" (Nancy Ward); "Advocacy in the Danger Zone" (interview with Debbie Robinson); "Self-Advocates and the Legislature: Making Voices Heard at the Capitol" (Walter Rupp); "Independence or Sponsorship: An Issue for Self-Advocacy Groups" (Bonnie Shoultz); "Who Can Teach Change Better?" (Beatrice Roth); "Elements of Choice" (Dennis J. Campbell); "Confessions of a Professional" (Mary F. Hayden); "A New National Organization? News from the First North American People First Conference" (Bonnie Shoultz); "Self-Advocates on Boards and Committees"; and "Tennessee Self-Advocates Conduct Quality Assurance Surveys." A list of 11 resources is included. (JDD)

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Feature Issue on Self-Advocacy

Volume 3(4) Winter, 1990/91

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Out of My Old Life and Into My New One

by Michael J. Kennedy

I grew up in three New York institutions. In 1982, when I was 21, I moved into a group living situation in the community called a supportive apartment. I lived with three other men with cerebral palsy, and we were supervised by staff whenever we were home. The supported apartment was much better than the institution, but in the six years I lived there I learned everything I could learn and was ready to be on my own. Also, the program was funded by Medicaid and had too many rules and regulations, like having to have goals and a service plan.

Michael Kennedy (right) at home with his roommates.

I knew what I wanted, but I needed help to get it. So I started talking to the director of the program about being on my own. I was listened to in one way, but not in another way because nothing was happening. What I had to do to get my point across was to threaten to move back into the institution near my family in the Adirondack Mountains area. The director got wind that I was actually going to do it, and the agency staff didn't want that. I know it would have been a mistake, and I didn't want to quit my job at the Center on Human Policy, but I felt my back was against the wall. That was the beginning of my getting my own home.

The agency told me about a new program they had just received funding for. It was called a Family Care program, but what it does is to match a person with roommates and the other supports he or she needs. One of the staff at the supported apartment, John, called me into the office one day and asked me if I would consider setting up a home with him and his roommate Gordy. I agreed, with the understanding that I didn't have to follow Medicaid rules or have a service

Life, continued on page 9

From the Editors:

Many people believe that individuals with disabilities are unable to speak for themselves. This belief is held by the general public as well as by professionals, policymakers, parents, and legal advocates. The self-advocacy movement has demonstrated that people with disabilities *can* speak for themselves and that they are valuable contributors to resolution of policy and service issues.

This issue of IMPACT gives people with disabilities the opportunity to educate others about self-advocacy. Twelve of its 17 articles are by individuals with disabilities who are self-advocates, or by other representatives of self-advocacy organizations. It includes information on self-advocacy strategies and examples of its impact on lives. It is our hope that these articles will affirm for all that people with disabilities have the right and ability to advocate on their own behalf, and will encourage more persons with disabilities to be self-advocates.

CONTENTS

Overview of Self-Advocacy	**2**	**Informed Choice**	**10**
Starting Self-Advocacy Groups	**3**	**Confessions**	**12**
Advocacy in the Danger Zone	**4**	**National Conference**	**13**
Self-Advocacy and Legislation	**6**	**Self-Advocates on Boards and Committees**	**14**
Independence or Sponsorship?	**7**	**Resource List**	**16**
Advisor's Role	**8**		

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A report from the Research and Training Center on Community Living and the Institute on Community Integration (a University Affiliated Program) at the University of Minnesota.

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A Short History of American Self-Advocacy

by Bonnie Shoultz

"We are speaking for ourselves; No one else can do as well...."

These first lines of a song written for Speaking for Ourselves of Pennsylvania aptly summarize the aims and achievements of the self-advocacy movement for people with developmental disabilities. The seeds of this movement can be traced back as far as 1968, when a Swedish parents' organization sponsored a meeting for people with developmental disabilities; the participants listed the changes they wanted in their programs, and gave their list to the parents' organization. During the next five years three other conferences were held around the world, designed as forums in which persons with developmental disabilities could speak on their own behalf about their needs and wants. A small group of people from Oregon attended one of those conferences, and felt strongly that the conference had not lived up to its promise because the professionals had done all the talking. As a result of their dissatisfaction, the People First movement began on January 8, 1974, at a meeting of Oregonians discussing the idea of organizing a conference run by and for people with developmental disabilities. Someone at the meeting said, "I'm tired of being called retarded—we are people first." "People First" was chosen as the name for the convention, which was held in October, 1974, in Oregon.

Between 1974 and 1984, self-advocacy groups sprang up all over the United States and Canada, and in other parts of the world including Britain, Australia, and Sweden. Many were sponsored by parents' organizations or service agencies, but others were formed as (or became) independently-operated groups. In 1984, the first International Self-Advocacy Leadership Conference was held in Tacoma, Washington.

The self-advocacy movement continues to grow. In the United States, several states have developed statewide organizations with numerous local chapters, and now there is serious discussion of forming a national organization. Statewide organizations include People First of Washington, with forty-five local chapters; Speaking for Ourselves in Pennsylvania, with six local chapters; People First of Nebraska, with eleven local chapters; People First of Tennessee, with twelve local chapters; Speaking for Ourselves of Colorado with fourteen local chapters, and many others. A directory of self-advocacy groups prepared early in 1990 by the Association for Retarded Citizens of the United States listed 380 groups—and there are many others they did not locate!

The maturity of the self-advocacy movement has consisted not just in the growth in numbers of groups, or in the development of statewide organizations, but also in the depth and complexity of the issues people are tackling and in the ways members are thinking about self-advocacy as a whole. For example:

- Speaking for Ourselves in Colorado planned and ran the First North American Conference on Self-Advocacy, held September 27-October 1, 1990.

- People First of Washington conducts statewide projects to help people with disabilities participate meaningfully in areas that affect their lives, such as their Individual Program Plan meetings and in decisions as to where and when they will move.

- People First of Nebraska has worked with the Nebraska Legislature to eliminate outdated terminology (words such as "feeble-minded" and "idiot") from all the Nebraska Statutes.

- People First of Tennessee has conducted a consumer monitoring project in group homes in Tennessee; they feel strongly that monitoring for quality should be done by consumers because the other monitors often do not even speak to people who live in these homes.

- Speaking for Ourselves of Pennsylvania has concentrated on getting members onto important policymaking boards and on negotiating delicate advocacy issues on behalf of vulnerable members. They have advocated for people at a facility in Philadelphia where many members lived, and were active in 1989 during a $6 million funding crisis in Philadelphia.

Representatives of these and other self-advocacy organizations are passionately committed to to what they do and have a depth of experience to share. As individuals and groups they are speaking for themselves and are at last being listened to. No one else can do as well.

Bonnie Shoultz is Associate Director for Training and Information at the Center on Human Policy, Syracuse University, 724 Comstock Ave., Syracuse, NY 13244-4230.

Starting Local Self-Advocacy Groups

by Nancy Ward

People First of Nebraska, Inc. has 14 local chapters across the state. As a member and a staff person of People First of Nebraska, I have helped to start 10 of these. The suggestions for organizing a local self-advocacy group contained in this article are based on my experience.

The starting point is finding a place where people who have a disability are (such as a sheltered workshop), and talking to people about your organization and what self-advocacy means to you. Ask them if they know what their rights are. If they don't know, then ask them if they think they should be able to say where they want to live or work. More than likely, they will answer "yes." Tell them this is one of their rights. Ask them if they can think of more. Then ask them if they know what goes along with having rights. If they don't, ask them what "responsible" means. Usually, they will see the connection between having rights and being responsible for your actions.

It's very important, when you are explaining self-advocacy to people, that you explain it so they can understand, but don't put people down by talking down to them. Give them examples of the self-advocacy skills you and your friends have. Ask them if they'd be interested in starting a chapter.

There are four things I think you need to start a chapter:

(1) The people you are trying to get interested in becoming members have to make the decision for themselves and they have to have a common goal.

(2) The group will need an advisor, someone from the community who gives support to the members. Ideally, the advisor should not be a person who works in an agency that serves the people in the chapter, because how are members going to address issues about staff if staff members are there? Sometimes, however, staff members can be helpful in getting a group started and in being a good advisor. The question is whether the person is willing to put the group's interests above the interests of the agency they work for.

(3) The advisor should not be paid to be the advisor. People who have disabilities already have enough paid people in their lives.

(4) The meetings should not be held in the workshop or group home. They should be held in the community (e.g., bank, library, church).

Now that you have asked them to start a group, explain to them how to get members. You don't need a lot of members to form a chapter. You can start with four people. Have the four people ask their friends if they'd be interested in becoming members, and just keep building it up. It is important to get the community involved. This is a good way to do that.

After you have been a chapter for awhile, you will want to elect officers. Usually, the officers are

Groups, continued on page 17

What Self Advocacy Means to Me

I didn't see myself as a person because of all the labels that were placed on me. Now I see myself as a person. People First taught me how to say "Yes, I have a disability and that's okay." People First wants people to say "person who has a disability" so people see us as a person first and our disabilities second. Until I got into People First, I didn't know how to direct my feelings. They had this commercial on TV for Special Olympics where they paraded kids across the stage. The image they portrayed was "Pity us because we have a disability." This made me mad so I yelled at the TV. A lot of good it does to yell at the TV! This is when my friends talked to me about joining People First of Lincoln. There I learned how to direct my feelings in a positive way. An example of this is when we wrote to the Joseph P. Kennedy Foundation, which sponsors Special Olympics, about how we feel about having people pity us. This is the worst thing people can do to people who have a disability because it doesn't give us an opportunity to grow. The commercial was taken off TV, perhaps because a lot of people wrote letters like ours. Now I do a lot of public speaking but it took me five years to get confidence in myself to do it. And this is why my self-advocacy skills are so important to me. -*Nancy Ward*

Advocacy in the Danger Zone

Note: During the First North American People First Conference, I had the opportunity to interview Debbie Robinson, President of the Board of Speaking for Ourselves. She has been working within the self-advocacy organization in Pennsylvania for five years. We talked about advocating for people in the Danger Zone.
-- Mary F. Hayden, IMPACT Editor

Interviewer: What is the Danger Zone?

Debbie: When you speak for someone, sometimes it is a job that entails dangers. [For example,] when you're talking about another person's health, when they are not getting the proper care. Sometimes I have to go and try to find out why that particular person is not getting medical care. [I have to do it] in way to not get him or her in trouble with the people who they live with.

Debbie Robinson addressing the First North American People First Conference.

Interviewer: Using your example about medical care, how would it be dangerous for the person for you to help him/her?

Debbie: Well, mainly because you are stepping in a medical situation. I am not a medical doctor...

I will use a story. I was involved with a member's medical health because she stopped coming to the chapter meetings. I found out she was sick and where she was at. She was not getting proper medical assistance...they were not taking proper care of her. I visited her to try to find out what was going on...I tried to find out as much information as I could. I tried to help this person get medical assistance. So, I paid a couple of visits, talked to some people, and tried to find out what was really going on. I found out she wasn't getting the care she needed to find out what was wrong with her. This person needed to go into a hospital setting to find out what was going on with her.

Interviewer: Why was she in danger while you were checking things out for her?

Debbie: The way the situation developed and seeing where she was at, and how they took care of her, and how she was treated while she was there, and trying to find out what they were doing to find out what was wrong with her. They didn't seem to be doing anything, or not much, because she was still sick. I didn't know. I was concerned.

So, I got in touch with a few contacts who were in the medical profession. I told them what I saw, the situation as I saw it, and my concern that no one was really looking at her to find out what was going on...We went to see the friend who was sick.[After the visit, additional contacts were made to enable the member to obtain the medical care that she needed.]

[In another example,] members asked me to come down to the institution...see where they lived and see the situation. It didn't look good either. They were not getting proper medical and dental care.

Interviewer: What type of concerns did your members have about the facility?

Debbie: We saw things there that would turn your stomach. It was a disgrace...

Interviewer: Were people afraid of other people doing something to them?

Debbie: Yes, that too. When you are dealing with people with disabilities [who live] in a setting like an institution...[where] they are not getting proper care, staff are not treating them right and some of them have been abused...something had to be done. On the other hand, we had to do it in a way that they [members] wouldn't get too much abuse from staff. It was not easy. They still had to live there. I can go home. They had to stay there.

You can't just jump into it. There are a lot of steps involved. It isn't something you can just jump into and say "I'm going to save you". It isn't like that. You have to do it slowly and step by step. It was too big for the chapter and our board had to get into it...I received permission from the board to step into it. The board backed me up. I had to report what was happening. It was touch and go. It's hard when you

see people crying. I've seen that. It's the saddest thing. You can't jump in. It was a slow painful process for our members.

Interviewer: What did you get for people?

Debbie: Not as much as I hoped. I was kind of disappointed. I wanted to close the place...We were able to get most of our members out that wanted out. We still have a few there that need to get out. The sad thing about this whole thing is that two friends had to separate because they were from separate counties[therefore, placed in their respective counties]. I want to get these two back together.

Speaking for Ourselves got the counties involved. We were the first ones to see what was going on in this institution. We called a meeting with the state and said, "Look, we have the evidence right here. Members are being abused. You have to do something about it. Something has to happen now...I'm not going to move until you say you will go down there and see it for yourself." So, for a couple of weeks people [from the state] went down there and saw the same things that we did. The same exact thing... Everybody came back with their report.

I really had to do something because members were really scared to go back there. The scary part was that they were afraid that they'd go back to their staff and get hurt again. Unfortunately, it did continue to happen until I got it straightened out. Slowly but surely we were trying to get things done, but we had to get the report from them [the state] to find out what was going on. That is why we had a weekly meeting with the state to say to them, "This is what is happening. You have to do something about it."

You have to be careful. You are dealing with peoples' lives. They are in situations where it is easy for you to pack up and leave. I had to go home and leave people there, knowing in my mind that I couldn't do anything. I would pray that no one else would

Danger Zone, continued on page 18

Tennessee Self-Advocates Conduct Quality Assurance Surveys

Twelve members of People First of Tennessee, Inc., conducted quality assurance activities at two agencies in Tennessee during the summer of 1989. They split into two teams, each of which looked at two group homes and two sheltered workshops. At the end of the site visits they presented the results to the agencies at an exit conference. Members of the two teams describe their experiences in the following interview. Those interviewed were Beth Sievers, State President; Samantha Sasnett, State Secretary; Sissy Heatherly, Past State Officer; Walter Phillips, Past State Officer; and William Goodman, Staff Self Advocate. The interviewer was Betty Henderson, Office Manager with People First.

Interviewer: Why did you all do the consumer monitoring surveys, what did you learn, and how was it valuable to the agencies surveyed?

Sissy: We've seen other people give a survey, but we didn't know what it was like. We did a survey so that we could be surveyors one day ourselves. It was important so that the centers and group home people can't walk on their [clients'] toes, so that we can see that things are going right.

Samantha: So they (the consumers) can have a better living and a better job.

Walter: To find out what they (the consumers) like about their agency and their jobs, and see what it was like to live in the group homes.

Bill: People First members ought to see what we can do so they can go out and do it also.

Beth: To show that we really do care about other people and the services they receive.

Interviewer: What kinds of things did you look for in the consumer monitoring survey?

Bill: I looked for wiring and things that were dangerous and I reported it to the staff. I read through the clients' files with their written permission. I found out some interesting things, their strengths and weaknesses. I asked questions about how much they get paid per piece or bimonthly. I asked the staff, not the clients. I talked to the

Survey, continued on page 17

Self-Advocates and the Legislature: Making Voices Heard at the Capitol

by Walter Rupp

Lobbying, policymaking, the legislative process. The domain of the professional lobbyist or politician? Not at all, according to members of Advocating Change Together, Inc. (ACT), a St. Paul, Minnesota, based self-advocacy group for people with developmental disabilities. ACT members have a proven track record at the Minnesota legislature. They have shown that not only does the consumer's perspective count, but that the consumer's voice and presence at the legislature is a powerful force to effect legislative change. In this article, ACT Board members share their expertise and experiences working with legislatures.

Gloria Steinbring, President of Advocating Change Together, says, "It is important for legislators to hear from consumers. That really makes a difference. Legislators hear from professionals a lot. When they meet with us (consumers) about issues affecting us, they really listen to us." She emphasizes the importance of getting involved in self-advocacy as the best way to learn how to influence the legislature. "ACT has been my education. I only finished 7th grade, but that doesn't mean I can't learn. I've learned how to be a lobbyist, how the legislature works, and how to teach others what I know."

Ken Tice, ACT Consumer Advocate, has testified before the Minnesota legislature many times. Here he speaks at an ACT meeting.

Richard Mathison, an ACT Board member says that there are a couple of ways to learn about and influence the legislative process in Minnesota. Richard says, "I learned about the legislative process by joining Advocating Change Together, and Partners in Policymaking at the World Institute on Disability." Richard points out that "hands-on" experience is the best teacher. Through writing letters to state legislators as part of his involvement with ACT, and visiting the offices of Minnesota's state legislators as part of his Partners in Policymaking training, Richard learned how to communicate his views on policies affecting him. "It just takes a little practice, then it's easy", says Richard.

Bill Nelson, also an ACT member, stresses the importance of knowing your representative. "We elect our representatives to speak for us. If we don't tell them what we think, they won't have good information to make decisions. We have to talk to them so they can do their jobs."

Cliff Poetz's experience with influencing the legislative process takes many forms. He is active with ACT, ARC (Association for Retarded Citizens), and UHF (United Handicapped Federation). At ACT and ARC, Cliff works hard teaching self-advocacy skills to people with disabilities. For example, at ACT Cliff has taught people how to give testimony at public hearings, and at ARC he helped with voter education for people with developmental disabilities. In addition to emphasizing the importance of grassroots organizing in order to be effective at influencing the legislature, Cliff also emphasizes getting involved with political campaigns. He says, "I get involved in the campaigns of politicians I support. Door knocking, distributing campaign literature, and helping with mailings at campaign headquarters; these are good opportunities to get to know the legislature and the issues." Cliff says that he used to be reluctant and somewhat fearful of getting involved in lobbying and giving testimony at hearings. "It takes time, but you get used to it. I'm not afraid to speak up now."

Ken Tice, Consumer Advocate with ACT, talks about giving testimony at the State Capitol. "I've given testimony many times. It's kind of scary at first, but it's not too hard. I think it's very, very important that consumers give testimony on bills and laws. They will listen to consumers because we are the best

Legislature, continued on page 15

Independence or Sponsorship: An Issue for Self-Advocacy Groups

by Bonnie Shoultz

There are basically two ways in which self-advocacy groups function across the country. Some, like several of the statewide organizations, are independent, autonomous organizations that have their own boards of directors and make independent decisions about their own affairs. Others, both statewide and local organizations, are sponsored by larger organizations such as an advocacy organization, a parents' group, or a service provider. For example, the Association for Retarded Citizens in a community may sponsor the group or even consider the group as one of its "programs" for which they receive funding. Or, a group home or sheltered workshop may sponsor a group on its premises. In either of these cases, the group may have an outside volunteer as an advisor, or may have a staff person of the sponsoring agency. This article lists the pros and cons of each model.

■ The Sponsored Group

The advantages for a group that is sponsored by (and perhaps even begun by) a larger organization are that finding things like a place to meet, a way to mail notices to members, and advisors are generally less difficult than if a group is independent. The sponsoring organization may also have knowledge and resources that can help the group to grow and learn about self-advocacy.

The disadvantages are that the group may have less opportunity to make its own decisions, to develop the skills of self-advocacy, to learn about the rights of people with disabilities, and to apply for funding in its own right than if it were independent. There have been instances where sponsoring organizations steered groups toward social activities, away from controversial issues, and away from real self-determination. There have been instances where the sponsoring organization feels it can do a better job of speaking for the people in the group than they can do for themselves. In a few cases, groups have left the sponsoring organization because of conflict over these issues.

Even if the sponsoring organization does not try to control a group or get into conflict with its members, it would be rare indeed for a sponsoring organization to put the interests of the self-advocacy group at the top of its list of concerns. In other words, it is likely to be very difficult for a self-advocacy group to put its own needs first when everything has to go through the larger organization.

■ The Independent Group

The advantages of independence for a group include the opportunity for greater control over its own affairs, such as making decisions, getting involved in controversies, and applying for funding for the projects it wants to carry out. It may be easier for the independent group to be part of a coalition of groups that all want the same thing. The independent group relies on itself, looking to its friends for assistance, but not depending on any one organization for survival. An independent group that is well-established has a better chance of continuing to promote its own goals in the long run.

One disadvantage of independence is that it may be more difficult for an independent group to get started. More people will have to do more work before the first meeting can be held. Another disadvantage is that if the advisor leaves, the group may be more likely to stop meeting. A third problem may be that the group may not have an easy time forming connections to the service system and the parent and advocacy organizations if it is independent.

Some independent groups have stopped meeting as a result of the problems listed above. But many other groups have worked through these problems and are pleased that they are independent. The members of many independent groups have formed good ties to other community organizations, to parent and advocacy groups, and to state legislators and other officials.

The groups that are independent feel that the path they've taken is the best way for a group to grow and become strong. But, they do recognize that the groups that are sponsored by other organizations have strengths and are a viable part of the self-advocacy movement, as well.

Bonnie Shoultz is the Associate Director for Training and Information at the Center on Human Policy, Syracuse University, 724 Comstock Ave., Syracuse, NY 13244-4230.

Who Can Teach Change Better?

by Beatrice Roth

In the early days when first asked to be a chapter advisor with Speaking for Ourselves, finding guidance material on my role was almost impossible. I was told, "Your members and your heart will teach you." How true, and the lessons began immediately.

As a guest observing my third monthly meeting of the group, the President once again welcomed me and expressed appreciation at my interest. Before fully understanding what was happening, I found that I had been nominated and voted in as a chapter advisor. I know now that this was the start of a whole new way of thinking, a way of reacting, or better still, not reacting.

To "assist" often meant to take over and do it myself. I learned that an advisor does not take over.

To assist others, to step in and help, had been instilled in me since childhood. But, to "assist" often meant to take over and do it myself. I learned that an advisor does not take over. An advisor supports and is a friend. The leadership role belongs to the members.

For example, my natural tendency is to push my own opinion of who's best suited for chapter officers, which are elected on a yearly basis. But, time has taught that an advisor listens first to what members have to say. Their finger is on the pulse of what is best for them. Those with top leadership abilities have already taken the foreground over the previous year and members have an instinctive knowledge of who can best represent the group.

When an individual speaks out on his or her own behalf, the message is from deep within. Who better knows what needs to be changed? Who can better describe the pain experienced and the frustration of unanswered needs? Who more has felt the effects of people ignoring their simple entreaties for everyday wants and desires? Individuals need only to be encouraged to step forward and speak out. Expressing reassuring faith in our members as individuals, exploring options, affirming abilities, is a vitally important role of an advisor. It can't be faked. It starts with listening as a true friend, prompting someone who has been devalued by society to expose their wounds, to trust you, to believe in him/herself. It's not easy for people that have been repressed and relegated to the background to freely speak out about what's hidden inside. But it's important for others to hear and understand the effect of their often unintended actions that hurt. The story needs to be told. Again, the advisor's part is that of a student learning from a teacher, our members, who can best instruct from self knowledge. Their insight gleaned through life's heartaches is the best teaching tool in bringing about change. An encompassing circle of experience, learning, educating, and support is shared by members and advisors alike.

One way the story is told is as members speak out on issues dear to them during the annual Speaking for Ourselves Conference. This event, planned, executed and presented from start to finish by Speaking for Ourselves members, is directed toward educating the world at large, parents, professionals and staff, on issues such as real jobs, community integration, and awareness of the many capabilities individuals with developmental disabilities offer to today's society. An event of this size is only successfully accomplished through the dedication, systematic planning, and teamwork of members from all chapters. Throughout this, the advisor is a strengthening backer, an affirming friend, providing transportation, paperwork and support backup. But, most important is the vital role of encouragement, being there when needed to prompt someone to take that scary next step.

...the advisor's part is that of a student learning from a teacher, our members, who can best instruct from self knowledge.

To me, my friends at Speaking for Ourselves inspire me to greater heights in life. It's why being an advisor is one of the greatest enjoyments of my life, just rubbing elbows with so many wonderfully courageous and determined people. It's a two-way street where each learns and each teaches, where all of us together in Speaking for Ourselves educate those in the world around us in the ways to a better life not just for individuals with disabilities, but for us all.

Beatrice Roth is Advisor for the Montgomery County Chapter of Speaking for Ourselves, in Montgomery county, Pennsylvania. Telephone: (215) 549-0550.

People First Members Teach "Transit"

People First members have always made transportation one of their top self-advocacy issues. People with developmental disabilities are (unfortunately) dependent upon local bus systems, or people who have cars, to get to where they need to go. In Seattle, Washington, people with developmental disabilities are dependent upon the regular METRO buses or on "specialized" (door to door and therefore not integrated) shuttle vans operated by METRO. Using the specialized METRO shuttle often involves calling 24 hours in advance, long periods of waiting for the shuttle to arrive, and other difficulties/barriers to an active and integrated community life.

People First of Washington, working with the King County (Seattle) Board for Developmental Disabilities and others, received a grant to employ people with developmental disabilities to teach others how to use the regular "mainline" buses. People First members are logical "bus trainers" because (1) they know the bus systems better than anyone else, and (2) they have a natural style of working with other people with disabilities because they have "walked in their shoes".

The "Transit Training Project" proved a great success. At the end of the Project, People First, working with others, was able to get METRO to take over the Project and employ people with disabilities to do the training. People First thought that it was better for METRO to directly hire people with disabilities as opposed to having People First do the Project. People First simply proved what a good idea it was to have people with disabilities do the training.

Contributed by People First of Washington, P.O. Box 381, Tacoma, WA 98401 • (206) 272-2811.

Life, continued from page 1

plan. I wanted to make my own decisions. I made it very clear that when it was time to leave the program, I could just go, no strings or questions asked.

As time went on, the coordinator of the Family Care program met with John and me. I told her what I wanted in terms of supports and a home. Part of her job is to help us find a place. The exciting part is that we have a friend who used to work for the agency who is into buying real estate. One day I was kidding with her and said, "Why don't you buy a house that would be easily accessible and I would rent it from you?" About a week later she told me she had bought a house! At first I thought she was kidding, but then when she took me and John over to see it I knew she was serious. We called the coordinator on the phone.

John and I then started meeting with her on a regular basis. It was actually pretty easy to set up the supports I would need, like physical therapy and my orthopedic doctor, because I could just take what I had from the apartment and transfer them to my new house. The supports I didn't have at the apartment were just added on. For example, I had to arrange attendant care with one of the agencies in town. Medicaid would pay for all of this when I was on my own because I kept my Medicaid eligibility.

Always keep in mind that it may not be as easy for someone else as it was for me to set it up. The important thing you have to remember is that you should be involved in every aspect from start to finish. You, the individual, must have the supports built around you, and not be made to fit into a program that wasn't designed just for you. This is true regardless of how severe your disabilities are. It's very impotant that you have the say about how your wants and needs are dealt with.

If you work at an agency, I would hope that you would go along with the individual on how he or she wants to live. You don't have to agree, but they have the right to live like anyone else.

I've lived on my own for the last two years. Through this period John and I have talked about moving down south. We both like the South for a number of reasons. One is that we both have family down there, and they have been asking us to move down there for quite a while. The most important reason is that both John and I felt we needed a change in our lives, we needed something new, and we needed to move on. So, we are moving to a town near Atlanta, Georgia. I am very excited about this move.

Michael Kennedy was formerly the Self-Advocacy Coordinator at the Center on Human Policy at Syracuse University, and is currently a consultant to the Center.

Informed Choice and Advocacy

During the next few years, several hundred Washington State residents with developmental disabilities will have the opportunity to move from state and private institutions (ICF-MR programs) and "regular" nursing homes into smaller community residential programs. These opportunities to move have been brought about by recent state and federal ICF-MR surveys, which found problems in the ICF-MR programs, and the Federal Omnibus Budget Reconciliation Act of 1987 (OBRA), which mandates "nursing home reform" in the residential placement of people with developmental disabilities.

Many of the individuals who have the opportunity to move do not have a family member or guardian to assist them in making choices about moving. The Division of Developmental Disabilities (DDD), which is our statewide service system for people with developmental disabilities, has contracted with People First of Washington to provide informed choice and advocacy services with these individuals.

"Informed choice" means having the knowledge and understanding about what the choices are, and freely being able to choose without pressure. The purpose of People First's Informed Choice and Advocacy Project is to recruit, train and provide ongoing support to volunteers who assist people to make informed choices about where they want to live as they face the opportunity to move. The volunteers assist people to make informed choices without pressure. Volunteers develop a personal relationship and a commitment to the person they are assisting. Volunteers spend time with the person and with others who have a significant role in the person's life. Volunteers are required to make a one year commitment, and to assist the person in making and carrying out their choices.

People First has developed a picture handbook for people who have the opportunity to move. It describes the four steps in making an informed choice: (1) knowing your rights about moving, (2) making a list of what you want in life, (3) looking at and visiting all the choices, and (4) making a decision without pressure.

In many cases, People First members have assisted people who live in the same state institutions where they once lived. This has been quite an experience for People First members, bringing back memories and being recognized by residents and staff who work and live at the institutions. This experience has enabled many People First members to not only assist others, but to talk about and "put to rest" their own pasts. We choose to think of this as growing as a person, gaining self-respect and value by helping others, and learning about the system of support services available to people with developmental disabilities. People First members have been invaluable in the Informed Choice and Advocacy Project because they have "walked in the shoes" of the people the Project is assisting.

Contributed by People First of Washington, P.O. Box 381, Tacoma, WA 98401 • (206) 272-2811.

Making the Most of Individual Program Planning

Most service systems now use IPPs (Individual Program Plans). As a self-advocate, you need support to get the best possible outcome from IPP meetings. Help matched to your individual requests may include:

- **Someone to go along to the meeting to support you, especially if you are going to challenge what the service providers want to do.**
- **Information about how the process works.**
- **Information about who will be there.**
- **Information about what data will be used (some people have been to meetings where the service providers used inaccurate information from outdated institution files).**
- **Help to say exactly what you want.**
- **Ideas about what's possible and what kinds of services could be available, and help to define high expectations for yourself.**
- **Connections to people who can help if you don't agree with the decisions of the IPP team.**

Adapted from Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves., published by the Research and Training Center on Community Living, University of Minnesota.

Elements of Choice

by Dennis J. Campbell

The elements of choice determine the success of an individual making choices in her or his daily living environment. These elements include one's level of educational experiences, one's lifestyle and a belief system that can lead to a creative life. Self-advocacy is a lifelong process that will give order to her or his world.

It was 1974 when I attended Highline Community College. The college was located in Kent, Washington. The campus was shaped in a linear formation, and I had just a manual wheelchair to scramble from class to class. Of course, the key element in planning my daily schedule was time, since I had to arrange my transportation from a nursing home to the college. Sometimes this proved to be a task.

Dennis Campbell at work in his home.

Another central element of planning was time to write out homework assignments, which took a certain amount of time since I type with a stick, thus I could only produce three or four words per minute. In a span of three years I was able to obtain an A.A. degree in general studies.

While I was still in school I made a conscious choice with regard to religion. Since science and history were my greatest passions, eventually some form of humanistic philosophy had emerged and I joined the First Universalist Unitarian Church of Seattle. Another central element of self-advocacy is the right to faith. And advocacy comes in when a person selects her or his belief system.

A week after I graduated from college, I moved to a residential center. The center was licensed as a nursing home at first. But a year later it became an I.M.R. facility. And this meant that the programs for persons with mental retardation were introduced. The board of the center was in constant battle to modify the programs to include things like physical therapy, and funding for powered wheelchairs and electronic communication devices, which were in need by the people with severe forms of cerebral palsy.

In the year of 1984, I was able to obtain a powered wheelchair from the state, which altered my world for the better. It took me more than two years before I was eager enough to take the chance and roam about in the community without an attendant ... going alone. Another key tool I was able to obtain from the state was my Touch Talker, which is a voice synthesizer. But I was not content to go back to a workshop where I would have to stuff Christmas stockings, drop paper clips into a drab grey box, or count those wooden headed yo-yo's! So I made the choice to go back to school, to get an Arts and Sciences degree. I then moved out of the residential center into an independent setting, where I have just one attendant who lives with me around the clock seven days a week. This living arrangement is slightly different from the norm where the average attendant gets two days off a week and might work in eight hour shifts. But due to the fact that my attendant and I are both artists and share common lifestyles...it works.

The center of advocacy and the methods that I employ is MAKING the choices. I rarely ask people for advice, or give in on my personal lifestyle. Nor how I should select my friends or if I should have a traditional job where I have to work 40 hours a week.

I chew the path of self-determination, which nourishes a creative form of life.

Dennis Campbell is on the State Board of People First of Washington and the local board of T.A.S.H. He is also assocated with various art organizations in the Seattle area.

Confessions of a Professional

By Mary F. Hayden

I am a social worker by trade. I entered the profession with the belief that social change could occur through the various methods of community organization, such as social protest, advocacy, lobbying, whistle blowing, and self-help action groups. Through the years I have participated in sit-ins, advocated for individuals and classes of people, and led self-help groups. Because of these experiences, I view myself as a "good guy".

When asked to plan and coordinate an all-day working conference on the issue of self-advocacy, I was excited to be given the opportunity to educate other professionals and to show them how to mend their ways. However, I found this holy campaign to be my own personal awakening. I was surrounded by many teachers. Through their actions and accounts of their personal experiences, they taught me that professional good intentions may hinder people with disabilities from speaking out for themselves. I found that even a "good guy" has room for improvement.

Prior to meeting the other participants at the conference, the word "client" would flash before me during conversations with them. I would become angry and tell myself that the correct term was "consumer". After I met with everyone at the conference, I was gently told that the "correct term" was "people with disabilities". Through working closely with everyone, the labels quickly went by the wayside. *Lesson #1: Do not label people. Get to know the individual for him or herself.*

As a member of the helping professions, I found myself wanting to help. I wanted to do things for people. For example, some people had not stayed in a hotel and, as a result, they did not know how to check in and out, charge meals to the room, and tip bellhops. Initially, I took care of a number of these activities. I eventually learned to explain the hotel "system" to people and let people take care of themselves. *Lesson #2: People have the right to make choices in everyday life. Practice what you preach.*

I wanted to protect people. This behavior ranged from telling someone that the area around the hotel was not safe to wanting to keep tabs on people. A series of events occurred that made me realize that my need to protect was a reflection of my focus on people's disabilities rather than their capabilities.

One afternoon several people decided to go to the Martin Luther King Center. I decided to use a rented car. One individual with a physical disability stayed behind. To my surprise, the person who "stayed behind" was at the Center waiting for us. I later found out that he preferred to travel independently rather than with a segregated group. Several other participants periodically left the group to either be by themselves or to meet new people. *Lesson #3: People have the right to discover, explore, and experience life.*

During the conference, the group worker within me became nervous; the group controlled the group process. Some people did not talk while others monopolized the time. A few people were overbearing, some were more articulate than others, and some were more socially skilled. Initially, I believed someone (a professional) had to work the group dynamics to insure that the most relevant information was brought to light. Due to this belief, I listened to people who were brief, accommodating, articulate, socially skilled, and focused. However, the facilitator was able to get beyond the veneer. He listened and heard each person's message. Every participant made a contribution to the conference and it was duly noted. *Lesson #4: Do not judge a book by its cover. Listen to the person.*

As these and other events occurred, I had a series of conversations with the other participants about when a behavior is a reflection of caring and support or when it is a reflection of control and over protectiveness. Through these conversations, people shared their experiences. They all provided examples of a professional's expertise and personal agenda overriding the wishes of the person with the disability. They gave accounts about how the social service system hinders personal growth. They shared moments where others judged their lifestyle. These conversations helped me to remember that I chose to work in the field to assist and support people with disabilities. They allowed me to re-affirm my belief that people should experience life to the fullest. *Lesson #5: The manner in which a person chooses to experience life may be inconsistent with our philosophy. These differences need to be simply acknowledged and appreciated. No value judgement is necessary.*

Mary F. Hayden is Research Coordinator with the Research and Training Center on Community Living, University of Minnesota, 108 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4848.

A New National Organization? News from the First North American People First Conference

From Thursday, September 27 through Monday, October 1, 1990, nearly 400 people involved in self-advocacy met at the YMCA of the Rockies in Estes Park, Colorado, to participate in the First North American People First Conference. People from 38 states and two Canadian provinces attended the conference. Speaking for Ourselves of Colorado planned and hosted the gathering, which was an enormous amount of work. The people at the conference had especially high praise for Patti Lampe, their advisor. Patti hardly slept before and during the conference and helped with everything. The Speaking for Ourselves members worked very hard, also. They seemed to be "on top" of everything!

The conference program included sessions on topics including, "A Look at How Self-Advocacy Got Started and Where We're Headed," "Changing the Community: What We Can Do to Make the Community a Better Place," "Making Friends in the Community and Helping Each Other, "A Chance to Learn From Other Groups," and "Where Do We Go From Here?" Each of these sessions was moderated by representatives of a self-advocacy group, with self-advocates as most the speakers. Advisors gave a couple of short presentations, too.

Other parts of the program included a "marketplace," where groups could sell or give away their printed materials, buttons, posters, shirts, tapes, and other items; a dance with a live band on Saturday night; a free afternoon for relaxing or exploring the Rockies; and great meals at the YMCA cafeteria.

Many people who came to the conference wanted to begin talking about starting a national organization. They thought this would be the best possible time to talk about it, because so many people from so many states were there. There was no time on the program to discuss the idea, so people spread the word that there would be night meetings. On Friday and Saturday nights, the people who had heard about it met in the living room of one of the lodges and had some very heated debates about whether and how they could form a national organization. They talked about how, until now, they have had local and statewide groups, but nothing that linked those groups together. They agreed that the time was ripe, and that they were ready to organize nationally. They decided on a five region structure, and that the people from each region would meet on Sunday to choose two people from their area to be on a Steering Committee that would make recommendations about a national organization.

The people in the night meetings wrote what they wanted on paper so that everyone could know about and understand it. When Sunday's meetings came, four of the five regions elected two people for the Steering Committee. The people elected were: Northeast region - Roland Johnson, Pennsylvania, and Elyse Collidud, New Jersey; Southeast region - Rick Betts, Tennessee, and Donald Hodges, Arkansas; Midwest region - Nancy Ward, Nebraska, and Gloria Steinbring, Minnesota; Southwest region - Ben Borroel, Colorado, and Ronald Smith, New Mexico. The Pacific region, which included people from California, Oregon, Washington, and Idaho, decided that they were not ready to get involved in a national organization. They felt that the next step for them was to strengthen their region. They did not elect representatives to the national Steering Committee, but instead elected a regional committee made up of five people from each of the states—20 people in all—to discuss ways of forming a strong region.

On Monday, everyone came together in the "Where Do We Go From Here?" session to talk about what their regions had done the day before. There was quite a bit of discussion about whether a national organization would succeed. Finally, a motion was made that read, "We authorize the Steering Committee to work out the details of a national organization within the next year, and come back with a report and recommendations at the 1991 conference in Nashville, Tennessee." This motion was passed, and the conference was adjourned.

People First of Tennessee will host the next national conference. It will be held at the Stouffer Hotel in Nashville, from August 30 to September 2, 1991. For more information, please contact People First of Tennessee at (615) 297-2734; their address is 32 Vancleve Lane, Murfreesboro, TN 37130.

Contributed by Bonnie Shoultz, Associate Director for Training and Information, Center on Human Policy, Syracuse University, Syracuse, NY.

Self-Advocates on Boards and Committees

More and more disability service providers and disability advocacy organizations are asking self-advocates to serve on councils, boards, task forces, advisory groups, and committees. The involvement of self-advocates in disability service organizations can make a positive difference for people with disabilities and help participants develop their leadership skills. But, when an organization only wants token disabled people or fails to organize its board and committee work for success, joining can be a frustrating waste of of energy. There are steps that self-advocates can take to decide if their involvement with an organization is worthwhile. There are also actions that self-advocacy groups can take to support their representatives, and strategies that disability organizations can do to effectively involve self-advocates.

When deciding whether to join an organization, a self-advocate should find out if the organization can really help people with disabilities and if it is set up for success in including persons with disabilities. The first step in screening the organization is finding out what the whole organization does. It ought to be clear how the organization's work will help self-advocates get more of what's really important for them. If the organization does things that are opposite to what self-advocates want, such as controlling people's choices or running restrictive group homes, the self-advocate needs to ask if the organization wants to change?

A second step is finding out what the board or committee or task force does. Sometimes they really make things happen, and sometimes they are just a rubber stamp. These questions should be asked:

- What decisions does it make?
- If it is giving advice, who decides about what happens to the advice?

It's also important that there be places on the board, task force, or committee for at least two self-advocates. This is helpful because:

- A more experienced person can go to meetings with a less experienced person, which builds leadership.
- If one person can't come, the other can represent the chapter and keep the absent person up to date.
- Even very experienced self-advocates feel more confident when they attend meetings with someone they know.

Some other suggestions for self-advocates who are joining committees, boards, advisory groups, or task forces are the following:

- Be sure you know what the expectations are, including finding out how often meetings are held, how long meetings last, and where meetings are held.
- Find out if members have to pay for anything and, if the organization pays people back for expenses, what is covered and how long does it take to get paid back.
- During meetings, listen carefully and wait until you pick up what's happening in the meeting before you speak.
- Find out what you don't know before you speak.
- Practice being concise and clear when you speak.
- If you don't understand something, ask questions. If you still don't understand, ask more questions.
- Take the time to decide what you think about issues the group is discussing. Talk to other members and advisors. Write down what you think.
- Report back to your self-advocacy group chapter and ask for ideas.

The self-advocacy group to which an individual belongs is important to their success in other organizations. The way the chapter's board and its meetings work teaches members how to participate in meetings and how to be better problem solvers. The training for officers and members builds skills useful in other organizations. Better ideas and more strength come from making time in chapter meetings for representatives to report on what happens on other boards and committees. This gives an opportunity for chapter members to have input. In addition, special meetings to compare laws, regulations, or plans with the

chapter's desires helps the chapter's representatives give better opinions at other board, committee, and task force meetings.

There are steps that the disability service organization can also take to ensure that self-advocates are effective members of boards, committees, task forces, councils, and advisory groups. First, when the group deals with complicated issues, it is helpful to have a person to be a facilitator. The facilitator's job is to help the self-advocates understand what is going on by reading and explaining written materials, to help self-advocates decide what they want to say, and to assist them in getting to and participating in the meeting. The facilitator only provides the specific help an individual needs. It is also crucial that the facilitator support the self-advocate to say what he or she thinks, not to say what the facilitator thinks.

During meetings participants should also avoid big words and jargon, write things clearly and in understandable language, and make information more accessible for people who have trouble reading by recording materials, communicating with pictures, and holding personal briefings.

Organizations with budgets should invest money in supporting the participation of people with disabilities by paying to do the following:

- Support facilitators.
- Be sure self-advocates don't lose money.
- Make adaptations to make it easier for self-advocates to participate.
- Provide financial support to the self-advocacy organization so representatives will have a strong foundation.

Any group works better for everyone when the following elements are present:

- There are clear ways to discuss things and everyone knows how decisions are made, versus getting bogged down in group politics.
- Meetings are not too formal.
- Staff help the group do its job instead of taking over or pushing their own ideas no matter what the board thinks.
- Time is taken to develop personal relationships so people don't feel intimidated, like "They are up there and I'm down here."
- People listen to one another with respect, with no put-downs and valuing what each person says.
- People can ask questions to clarify what they don't understand.
- Small groups are assigned to talk things over and get things done so people can really discuss issues and influence each other.

By taking the time and care to screen organizations, support chapter representatives, and structure meetings for effective participation by self-advocates, people can work together to improve life for individuals with disabilities. It requires a desire to succeed, a willingness to accept new ways of doing things, and a mutual respect for all members of our communities.

The suggestions in this article are taken from the comments of participants in the workshop, "Assisting People with Developmental Disabilities to Speak Effectively for Themselves," held during the 114th Annual Conference of the American Association on Mental Retardation, May 30, 1990. Each of the 18 workshop participants has extensive experience in developing self-advocacy groups for persons with developmental disabilities.

The complete record of the workshop discussion is published in Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves, published by the Research and Training Center on Community Living, in the Institute on Community Integration at the University of Minnesota (see the Resource List on page 16 for information on ordering the booklet).

Legislation, continued from page 6

experts on disability." Ken encourages others to get involved. "It's fun to give testimony and anybody can do it. Don't be afraid to ask for help if you need it." When asked where consumers could find help, Ken says, "That is easy, just call ACT or the United Handicapped Federation."

ACT members clearly demonstrate that influencing the legislative process need not be for high power politicians and lobbyists. People with developmental disabilities can be a powerful force at the legislature.

Walter Rupp is Community Organizer with Advocating Change Together, Inc., 1821 University Ave., Suite 363, St. Paul, MN 55104 • (612)641-0297.

Resources on Self-Advocacy

From *Speaking for Ourselves:*

• **Speaking for Ourselves cassette**. Contains the song, "Speaking for Ourselves", the unofficial anthem of the self-advocacy movement, and "The Ballad of Wisdom's Prey," a haunting indictment of institutions. Cost: $5. Order from Speaking for Ourselves, One Plymouth Meeting, Suite 625, Plymouth Meeting, PA 19462.

From *People First of Washington:*

To order materials from People First of Washington, write People First of Washington, P.O. Box 381, Tacoma, WA 98401, or call (206) 272-2811.

• **A Handbook for People Thinking About Moving.** This handbook can help people make informed choices about where they want to live and work.

• **The Volunteer's Handbook for People Thinking About Moving**. Designed to help volunteers help individuals with disabilities make informed chocies about where to live.

• People First of Washington has a number of other printed materials available, including a newsletter, a handbook for group officers, a handbook for group advisors, and information on assertiveness.

From *Advocating Change Together (ACT):*

• Advocating Change Together (ACT) has a resource library with a number of materials available. For more information contact Mary Kay Kennedy, ACT, 1821 University Ave., Suite 363, St. Paul, MN 55104. Telephone: (612) 641-0297.

From the *Institute on Community Integration at the University of Minnesota:*

To order materials from the Institute on Community Integration, write to the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. Orders must be prepaid. Make checks payable to the University of Minnesota. For additional information call the Publications Office at (612)624-4512.

• **Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves**. This report contains the discussion from the workshop, "Assisting People with Developmental Disabilities to Speak Effectively for Themselves," held at the 114th Annual Conference of the American Association on Mental Retardation, May, 30, 1990. It contains the comments of 18 participants, all of whom have extensive experience with self-advocacy. Cost: $3.

• **IMPACT: Feature Issue on Consumer Controlled Housing**. This newsletter focuses on issues, strategies, and options in consumer controlled housing for persons with disabilities. Cost: First copy free, each additional copy $2.

• **Recommendations from the National Conference on Self-Determination**. Contains recommendations by the 60 participants in the January, 1989, conference. Focus is on improving services from the U.S. Office of Special Education and Rehabilitative Services and other agencies. Cost: 1st copy free, each additional copy $3.

From *Human Policy Press:*

To order materials write Human Policy Press, P.O. Box 127, University Station, Syracuse NY 13210. All orders must be prepaid and payable to Human Policy Press.

• **Our Voice is New: All About Self-Advocacy.** This is a slide show that explains what self-advocacy is, why it is important, what the major issues are for self-advocates, and what self-advocates do. It is for people with developmental disabilities who want to learn about self-advocacy and for others who want to support self-advocacy. Includes 114 slides, script and tape cassette. Cost: $50 plus $2.50 shipping/handling.

• **Self-Advocacy Media Package**
A media package on self-advocacy. In addition to the slide show," Our Voice is New", this media package includes three posters, two "Label Jars, Not People" buttons, and an annotated bibliography. Cost: $55.00 plus $3.50 shipping and handling.

• **Materials on Self-Determination** includes an overview article on self-advocacy and a short annotated bibliography. Cost: $1.30 plus 10% postage and handling. To order this publication, write: Center on Human Policy, Syracuse University, 200 Huntington Hall, 2nd Floor, Syracuse, NY 13244-2340

Survey, continued from page 5

clients about whether they liked it there or whether they wanted to work somewhere different.

Sissy: I had to look for things that were important that I wouldn't normally look for: handicapped accessibility, bathrooms and floors. It's important for people with handicaps to have that, important to make sure a wheelchair can get around.

Interviewer: Why do you think people with disabilities should do surveys?

Bill: Parents are on the Board (of most agencies) — consumers are not. People First members and other consumers should be on the Board of Directors and survey teams. We want to know what is going on and what's not going on.

Interviewer: What do you think you taught the people at the agency about surveys? What did you want to prove?

Beth: We wanted to prove that we can speak up for ourselves. I don't really need staff speaking for me.

Bill: We aren't just disabled people. We are speaking up for ourselves and speaking out for ourselves. Clients can be on the Board and give the agency feedback as consumers because they have the right to be on it — they work at the place. If their parents are on the Board, I don't see why they shouldn't be on the Board too because that is their right.

Interviewer: Do you think it makes sense to have parents as "consumers" on the Board?

Bill: No! Because they don't work at the shop. They stay at home or they have a job. The clients should be on the Board because they know what's going on more than their parents know. Some of the staff may know, but they don't always tell them.

Interviewer: What would you do differently on your next survey?

Team: Speak up more, look around more — at staff files and policies and procedures, talk to the clients of the agency more about what they like and don't like and get other team members to participate more. Mainly encourage people in the program to speak up more, to take more time to do the survey and study more ahead of time.

Contributed by Ruthie-Marie Beckwith, Staff Advisor, People First of Tennessee, P.O. Box 121211, Nashville, TN 37212-1211 • (615)297-2734.

Groups, continued from page 3

President, Vice President, Secretary, and Treasurer. Many chapters also include the Past President as an officer.

You might want to have an open meeting and invite your community to a meeting, or join an organization such as the Kiwanis, Jaycees, or Lions Club. These are good ways for you to educate your community about People First and people who have disabilities.

You will want to decide where and when your meeting will be. The meeting room should be accessible for people in wheelchairs. When deciding when and where, remember that you will need to find a place where most of the members can walk or take the bus to get there. Also remember that people have to work, so have the meeting when most of the members can come. Have members start keeping a calendar so you don't schedule two things at once. Have your advisor show you how to get a meeting room.

Here are some things an advisor can help with:

- Help members learn how to run their own meetings.
- Help provide transportation.
- Show members how to solve their problems.
- Give suggestions on how to ask people for help when they don't know how to do something.

What is important is that the members and advisor develop a trust between each other. This way the advisor can let people grow at their own rate. If people can't learn at their own rate they will just become frustrated and not gain confidence in themselves.

Through following these suggestions for organizing a local self-advocacy group, people can work together so that others come to see us as people first.

Nancy Ward is the Self-Advocacy Organizer with People First of Nebraska in Lincoln.

Danger Zone, continued from page 5

get hurt...You know the situation. I'm dealing with peoples' lives. I had to be careful. That is how you have to look at it. It is truly hard to advocate for someone. You go into meetings with them. Some of them tell the truth, some of them don't. You get caught sometimes. It is not easy.

Interviewer: Were you able to do things to protect people on a long-term basis?

Debbie: We had people go there constantly. They knew that we, my organization Speaking for Ourselves, were involved, getting the state involved and checking this institution out. So, what they did was stopped us from going to the rooms. We could only go to the lobby. They knew someone was going up there, whether it was us or someone from the state or region. Everybody from counties visited...We had meetings constantly on this issue. Reports were coming back.

The chapter meetings were very important. They were a safety net for them until we got other members talking about [the problem]. Confidentiality is the most important thing when you are working or dealing with people with disabilities.

Interviewer: How was it a safety net? Was it a place where they knew they could talk?

Debbie: Yes. They could tell us...I could get their confidence. It wasn't an easy thing to talk about. I could build confidence with the other members. Other people at the meetings were afraid to say what was happening. They were scared because they had to go back there.

I told them it was not going to be an easy process. We will work on it. It was very painful. A slow process. A slower process than what I was ever involved in. Then I invited people who worked in the system to the chapter meetings so they could hear from the chapters what was going on. The officials needed to know what was going on. I invited them, but I told the chapter that a person was coming down. Told them what [the officials] do...I had to talk to them [people from the mental retardation system] first. I told them that when they come to my chapter meeting, whatever you hear, I don't want it to go to the staff. If you do, people will get hurt. So they heard the stories. I had a list of things that were happening and I would bring it back to the state. I would tell them what was still happening.... We involved them in that so they could hear their stories. It was hard to get them to talk about, but it was the most important.

The process wasn't going fast enough. They [the state] were trying to work with the institution to change it. Try to make it better before they can try to move people. When you try to move people out of an institution, you have to have a place to put them.

Interviewer: It sounds like self-advocacy is a long process. It isn't an overnight success.

Debbie: Yes. I helped a member move from his parental home. It started when he entered the hospital. He called me and told me where he was. We did not hear from him for months. We tried to get a hold of him. His mother didn't allow us to talk to him. He was sick at home. They tried to get nurses over there, they tried to get him care because his mother was old. So, they tried to get care for him, but a sibling wouldn't let them in.

He called me from the hospital and told me things. It was bad at home for him...He started telling me stories about his living arrangements. He begged me, "Don't send me home. I don't want to go home. I can't. It is bad at home." So, it was a bad situation. He was worried and upset. I had to try and calm him down. I had to try to work with the mental retardation system. Got in touch with a few people. We worked with them and him all week. I finally got him hooked up with people. That was a long process. [It took about three weeks.] The Danger Zone for him was that if I had not acted and they discharged him, he was afraid he was going home.

I had to keep him [in the hospital] and not send him home. He was begging me. He was really concerned that he was going home. It was really hard. He couldn't talk clearly enough. They [the people from the mental retardation system] had to verify what was going on. I had to make a lot of phone calls. I connected [another sibling] with the people in the system. What was scary for both of us was he was getting close to discharge. We had to act quickly. So, an agency took him [and provided him with a community living arrangement.]

Interviewer: So, that worked out real well.

Debbie: Yes, I'm still trying to get him medical care, he is still in a chair. He hasn't had any therapy. So, it is still going on.

Interviewer: When someone calls you and asks for your help, do you go through certain steps to provide assistance?

Debbie: No. I have to find out what is the problem. I have to find out all of the information. What is the problem in general. If it is an emergency, then I have to react to the situation quickly.

Interviewer: If it is an emergency, what do you do?

Debbie: I first think about it, this person is in real danger. My first reaction is to contact a person: a lawyer, a person in the system, or my organization. I call right away. If it is medical, I will call a friend (who is a doctor). If it is something else, I will call someone in the mental retardation system. Then I get down to see the person or get someone to check out the situation for me. Is this really a diehard situation? You need to see it firsthand...I try to react pretty quickly and get connections started. Try to cut through the red tape as quickly as possible

Interviewer: When you are working with people in a Danger Zone, what do self-advocates have to remember?

Debbie: Self-advocacy people have to remember that you are going to come across a situation where you have to be really careful how you handle it, not be so hasty, and be patient. You have to be careful. You have to think about the people you are trying to help. The person is the first priority. They are living in that situation and you have to be really careful. You are dealing with people's lives.

Interviewer: Did you ever work with someone who wanted something, you honestly disagreed with them, and you were uncomfortable with the decision?

Debbie: Not too many times. If I don't think it is right for them, I'll explain it. Yet, I have to remember that is what they want.

Interviewer: If they insist?

Debbie: That is a hard question because it depends upon what it is. For example, if someone wants to live with a family member and we know it isn't going to happen but he really wants it, it is sad. We try to tell them, be as honest as possible, that it is hard to live with a family member. If the family member doesn't really want to take care of [the person with a disability] for certain reasons or is not equipped to take care of them, then you have to tell the person the reason. You have to be honest and truthful. It hurts, but you say to him or her that you will try to get them into a better place...

Interviewer: What about someone who wants to move into an institutional setting?

Debbie: We will tell them it is an institution like where you came from. If they really want it, we take them to see the place... We ask them if they want to stay in that type of setting. We try and give people options, better choices...

Interviewer: So, you give them information, and choices. You will respect their decision.

Debbie: Yes. We have to. We will stay in contact to see what is happening.

Interviewer: Anything else you want to say to advocates who work in the Danger Zone?

Debbie: Think about the situation. There are all kinds of problems. You will have to handle each in a different way. Sometimes it helps to go to people and get advice before you jump into it. Talk to other self-advocacy people that know about certain things. You need a general idea about a situation. Some people have a better idea about a situation than you do....

Interviewer: What advice can you give to other self-advocates about how to take care of themselves and avoid burnout while working in the Danger Zone?

Debbie: First, it is a hard question. You tell the person [with the disability] you can't really help them this week, but you will connect them with a friend of yours who will help them. You can't do it all by yourself. You need help. You have to be careful who you connect with who. How trustworthy is that person.

You'll know when you can't go on. Your body will tell you. Sometimes you need to take some time. Like a weekend. You let people know when you are going to be away. You have to cover your bases. Make sure you connect people up with one another.

You have to make sure you know what you are getting into. You can't go in blindfolded. That is a Danger Zone. You go in blindfolded, you are going to get a few surprises ...You have to go in with open [eyes]...Otherwise, you will get into trouble.

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In this issue . . .

- **Three people talk about living as self-advocates.**
- **The self-advocacy movement in the U.S.**
- **How to start local self-advocacy groups.**
- **Self-advocacy in the danger zone.**
- **How self-advocates influence legislation.**
- **Independent vs sponsored self-advocacy groups.**
- **How to be an advisor for a self-advocacy group.**
- **Projects around the country.**
- **Confessions of a professional.**
- **The 1st North American People First Conference.**
- **Self-advocates on boards and committees.**
- **Resources for further information.**

IMPACT
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